



Peeps!

You've probably been given this information pack because your baby has experienced a HIE (hypoxic-ischaemic encephalopathy) event. We're here to let you know about some of the support that is available and to reassure you that you're not on your own.

Being in hospital can be tough going and there's lots to take in and learn; we're not about to baffle you with medical terms - we'll try and keep things simple and help you through any difficult days.



What is Peeps?

Peeps is a charity which was set up in 2018 by Sarah & Steve. Here's a quick note from Sarah to explain why:

"We found ourselves in the world of HIE when our daughter was born in March 2015 - she stopped breathing shortly after birth and, without any warning, our NICU journey began.

Neither of us had heard of HIE before, none of our friends or family had, and let's be honest, it was a scary time. I Googled it (going against the advice of all the nurses of course!), and luckily found a Facebook forum for families. If it hadn't been for that group and the advice and information offered by other mums and dads, I think we might still have been wondering what on earth was going on!

"So, we wanted to change things a bit, reach out to families in the early days, and bring the information to them, rather than them having to look for it."

Every HIE journey is going to be different, but there can be similarities and celebrations, as well as the uncertainties and worrying times. Peeps can be along-side you whenever you need us, whether that's today, next week or in a few months time.



What is HIE?

HIE stands for hypoxic-ischaemic encephalopathy, and put simply, is a lack of oxygen to the brain. This can cause injury, and the severity of this can vary greatly (often given a grade from 1 which is mild to 3 which is severe). Your doctor will probably have explained this in more detail, and may do tests to determine the extent of any damage. (One thing to remember though, is that babies have a tendency to do their own thing, despite what any results may suggest!).

There are many potential causes of HIE, such as placental abruption, umbilical cord- prolapse, uterine rupture and shoulder dystocia. There are lots of other possible causes (too many to list here) so best to seek a medical opinion if you need further details.

HIE affects 3-4 babies in every 1,000
– you’re not alone!



From experience, HIE isn’t really that well known despite the number of families it impacts each year.

Peeps is trying to raise awareness, so that others know more about it and that more people affected by it can get the support needed.



Contact details



There are lots of ways you can get in touch with us and we’ll always try and respond as quickly as we can (we don’t have any big call centres though so please don’t be put off if you need to leave a message – we’ll always try and pick up asap!). You can:

Give us a bell on 0800 987 5422

Drop a text on 07520 633 774

Ping over an email to info@peeps-hie.org

Find us on Facebook and send a message, just search “Peeps - HIE”

We understand that sometimes making the first phone-call, or sending the first message can be daunting. We promise though that we aren’t scary, and you’ll always get a warm welcome.

We’re working on a whizzy new website too so that you can easily find info at any time, day or night (sleep is sometimes a rare thing on NICU isn’t it?). The address is www.peeps-hie.org so keep an eye out for it being updated.

Buddy support



If you think it might be helpful to meet up with a mum or dad who has been through the same experience, then we can put you in touch with a “buddy”; you’ll be paired with a local family (wherever possible) who has experienced HIE and are happy to meet up. We’ll even throw in a coffee or two for you!

Don’t worry though if meeting up feels a little too much at the mo – you can still have a buddy for phone or email contact if you prefer.



Counselling

This group is set up by parents, and whilst we have experience and can always lend an ear, we're not trained professionals. If you feel you would benefit from speaking to a trained counsellor, please get in touch so we can help you further.

Useful links

There is a wide range of support out there for parents - some useful links as a good starting point are:

HIE Network Forum on Facebook

www.facebook.com/groups/thehienetwork

Hope for HIE - New to HIE on Facebook

www.facebook.com/groups/newtohie

The Rainbow Trust

www.rainbowtrust.org.uk



A helping hand through NICU

With the input from some fellow HIE families, we've put together a few hints and tips to try and help during those early days (and beyond).

- Ask questions - never ever feel that you are being a nuisance! As a parent to a baby/child affected by HIE, there are probably lots of things going around in your mind. Make sure that you are fully informed as to what is going on, and if anything isn't clear then ask the consultant/doctor/nurse etc. to run through it again (and again if needed!) until you are.
- If friends or family offer to help, take them up on it! It can sometimes be easy to say that you're fine, or you don't want to accept help, but it's really important to try and look after yourself, while you're looking after your little one. Ask them to bring you a home-cooked meal, or a supermarket dine-in-for two tea...it's easier said than done but trying to have some proper food rather than snacks can help keep your energy levels up.
- Ask the hospital (if they haven't told you already) if there is a parking permit available. It can be expensive at the best of times, but many hospitals offer a discounted or free pass for parents who have a baby in NICU.
- Remember to try and get some "you" time (another thing that's easier said than done). Whether it's time to sleep, grab some fresh air, or chat to a friend, it's important and you shouldn't feel guilty. The NICU nurses won't judge you for taking some time out (in fact most would encourage it!) - your little one is in safe hands and you'll be a bit more refreshed when you go back to them.
- Keep a journal - writing things down can help clear your head, and also means you can look back on your journey. Keep a track of every little development and take each day at a time.
- Talk - whether it's to your partner, your family, your friends, your GP, or to Peeps...it's ok to feel how you're feeling; we're here to listen and help where we can.

